The Incidence of Childhood IDDM in New South Wales, Australia

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OBJECTIVE — To determine the incidence of insulin-dependent diabetes mellitus (IDDM) in children 0–14 years of age in the state of New South Wales, Australia, which has a total population of 5.73 million.

RESEARCH DESIGN AND METHODS — We established a prospective register, identifying 361 incident cases over a 2-year period (1990–1991) with two independent sources of case ascertainment. The primary source was the reporting of newly diagnosed patients by physicians and diabetes educators. The secondary source was a subsidized syringe scheme.

RESULTS — Using the capture-recapture method, ascertainment was estimated to be 99.4% complete. The age-standardized incidence rate was 14.5 per 100,000 person-years (95% confidence interval: 13.0–16.0). No significant differences were found when comparing the first and second years of the register, boys and girls, geographical areas, or Aboriginal and non-Aboriginal children. There was seasonal variation in the onset (with more cases in winter), which was evident in the 10- to 14-year age-group ($P = 0.01$), but not in younger age-groups. A first-degree relative was already affected in 6.9% of the cases. No significant difference was noted in the age at onset when comparing cases with and without an affected first-degree relative.

CONCLUSIONS — The incidence of childhood IDDM in New South Wales is similar to rates found in other predominantly Anglo-Saxon populations. IDDM occurs in Aboriginal children with a frequency comparable to that in the rest of the population.

The incidence of childhood insulin-dependent diabetes mellitus (IDDM) varies greatly worldwide, ranging from 2/100,000 in Japan (1) to more than 35/100,000 in Finland (2). Such comparisons may contribute to the identification of genetic and environmental factors causing the disease. To add to the international comparison of incidence rates with standardized methods (3), we established a prospective incidence register for the 0- to 14-year age-group in the state of New South Wales (total population is 5.73 million; area is 801,600 km^2).

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IDDM, insulin-dependent diabetes mellitus; NIDDM, non-insulin-dependent diabetes; NDSS, National Diabetes Supply Scheme; CI, confidence interval.

RESEARCH DESIGN AND METHODS

Inclusion criteria

The data presented in this report come from the first 2 years (1990–1991) of an ongoing incidence register. Inclusion criteria for the register are *1*) diagnosis of IDDM by a physician, 2) diagnosis (defined as the date on which insulin treatment commenced) before the 15th birthday, and 3) place of usual residence within New South Wales. Ten children (2.7%) were excluded because they had other forms of diabetes: three secondary to cystic fibrosis, two with non-insulin-dependent diabetes (NIDDM), two with post-pancreatectomy diabetes, one with lipoatrophic diabetes, one with neonatal diabetes, and one with chemotherapy-induced diabetes.

Validation of case ascertainment

Incident cases were ascertained prospectively. In Australia, childhood diabetes is usually treated by hospital-based pediatricians and endocrinologists. The primary source of ascertainment was case reporting by pediatricians, diabetes educators, endocrinologists, and nurses, who received a newsletter every 3 months to remind them about the register and inform them about its progress. Relevant health professionals in adjacent states were also contacted, and we identified nine cases residing in New South Wales but treated elsewhere. In addition, the project received publicity in five professional publications, and patient associations informed their new members about the study.

An independent, secondary source of ascertainment was made available by the National Diabetes Supply

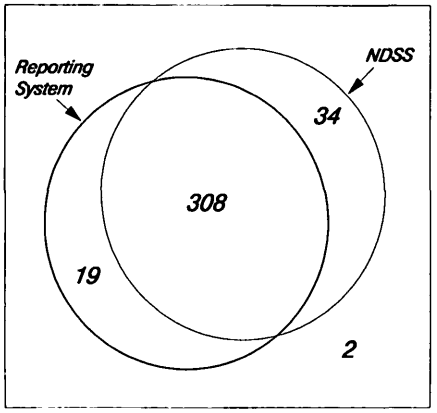

Figure 1—*The number of incident cases of childhood IDDM identified for a 2-year period by two independent sources of ascertainment. The primary source was the voluntary reporting of cases by physicians and diabetes educators. The secondary source was the NDSS. Using the capture-recapture method, it was estimated that two cases were missed by both sources.*

Scheme (NDSS). Patients register with this scheme to receive syringes, needles, and test strips at a considerably subsidized cost. The cases identified by the primary source were compared with those registered with the NDSS (Fig. 1) and the completeness of ascertainment was estimated using the capture-recapture method (4,5).

Data collection and statistical analysis

Basic data on date of birth, date of diagnosis, sex, and statistical local area (6) of residence were available on every case. Additional data, including ethnicity and family history of IDDM, were obtained through a questionnaire completed by the parents. Responses about family history requiring clarification were followed-up with a telephone interview. For confidentiality, the questionnaire was not administered to cases identified solely by the secondary source. Questionnaires were completed for 93% of the cases identified by the primary source or 84% of all cases. Questions about ethnicity were worded in the same way as those in the Australian Census (7) to allow comparison with census data. The most recent available population data on ethnicity was from the 1986 census. Incidence rates were calculated using data from the 1991 census (8). For the 0- to 14-year age-group as a whole, age-standardized rates were calculated to allow comparison with other countries with different age structures. This was achieved using the direct method, assuming a standard population with equal numbers in each category 0–4, 5–9, and 10–14 years of age. Confidence intervals (CIs) were based on the Poisson distribution (9). The statistical significance of seasonal variation was evaluated using Roger's test with 12 (month) categories (10).

RESULTS

Completeness of ascertainment

Case ascertainment from a combination of both sources was 99.4% complete (Fig. 1). There was no difference in the completeness of ascertainment between the first (99.4%) and second (99.5%) years of the register.

Incidence

During the 2 years studied, 361 new cases under 15 years of age (180 girls and 181 boys) were identified. The age-standardized incidence over the 2-year period was 14.5/100,000 person-years (95% CI: 13.0–16.0). Table 1 shows annual incidence rates by age-group, sex, and year. There were no significant differences between the first and second years of the register or between boys and girls. Figure 2 shows age-specific incidence rates with a peak at 12 years of age.

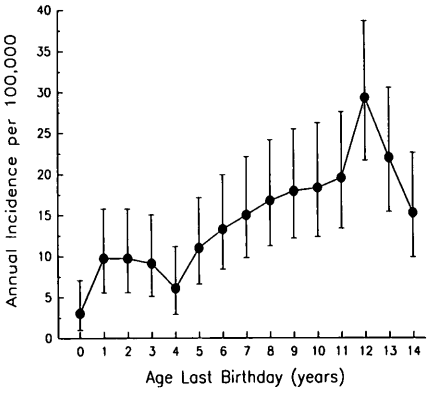

Figure 2—*The age-specific incidence of IDDM (per 100,000) in New South Wales. Values are the means of 2 years (1990 and 1991). Error bars are 95% CIs.*

Seasonal variation

There was a seasonal incidence variation with more cases diagnosed in the winter months ($P = 0.03$, Roger's test). When age-groups were analyzed separately (Fig. 3), this cyclical pattern was evident in the 10- to 14-year age-group ($P = 0.01$), but not significant in the younger age-groups.

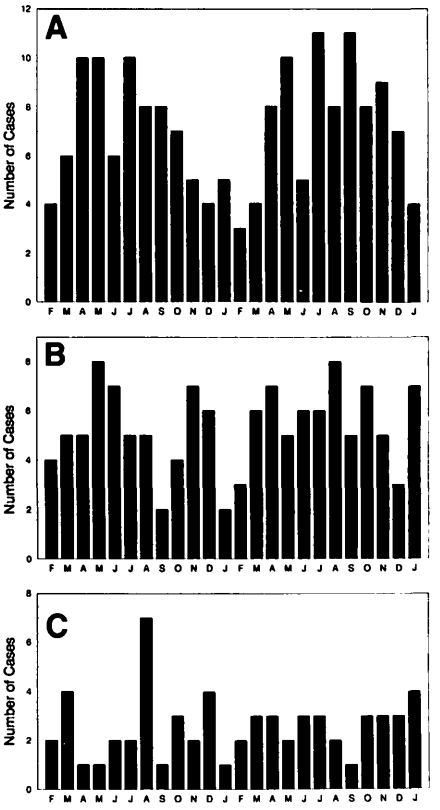

Figure 3—*The number of incident cases of IDDM in New South Wales occurring each month over a 2-year period. In the 10- to 14-year age-group (A), there was a significant seasonal variation (P = 0.01, Roger's test) not seen in the 5- to 9-year age-group (B; P = 0.5) or in the 0- to 4-year age-group (C; P = 0.9).*

Table 1—*The incidence of IDDM in New South Wales*

Age-group (years)	Denominator population	1990 n	1990 Annual incidence per 100,000	1991 n	1991 Annual incidence per 100,000
0–4					
Boys	209,910	13	6.2 (3.3–10.6)	15	7.1 (4.0–11.8)
Girls	200,168	17	8.5 (5.0–13.6)	17	8.5 (5.0–13.6)
Total	410,078	30	7.3 (4.9–10.5)	32	7.8 (5.4–11.0)
5–9					
Boys	220,887	35	15.8 (11.0–22.2)	31	14.0 (9.5–19.9)
Girls	210,277	25	11.9 (7.7–17.6)	37	17.6 (12.4–24.3)
Total	431,164	60	13.9 (10.7–18.0)	68	15.8 (12.3–20.1)
10–14					
Boys	209,412	43	20.5 (14.9–27.7)	44	21.0 (15.3–28.2)
Girls	198,735	40	20.1 (14.4–27.4)	44	22.1 (16.1–29.7)
Total	408,147	83	20.3 (16.3–25.3)	88	21.6 (17.4–26.7)
0–14					
Boys	640,209	91	14.2 (11.5–17.5)	90	14.1 (11.4–17.4)
Girls	609,180	82	13.5 (10.8–16.9)	98	16.1 (13.1–19.7)
Total	1,249,389	173	13.9 (11.9–16.1)	188	15.0 (13.0–17.4)

Data are annual incidence per 100,000 (95% CIs). Denominator population data are from the 1991 Australian Census (8); 1990 is 1 February 1990 to 31 January 1991; 1991 is 1 February 1991 to 31 January 1992. Age-standardized rates are shown for the 0- to 14-year age-group.

Geographical variation

When incidence rates for different regions (6) were compared, no evidence of geographical clustering existed. There was no significant difference when urban areas with a population ≥100,000 (14.0/100,000, 95% CI: 12.3–15.8) were compared with the rural balance of the state (15.6/100,000, 95% CI: 12.9–18.9).

Ethnic background

Aboriginal children constituted 1.6% (5 of 305) of the cases compared with 1.9% of the denominator population (11) ($\chi^2 = 0.13$, $P = 0.7$). The clinical features and autoantibody levels of these Aboriginal cases were incompatible with a diagnosis of NIDDM (data not shown). Among Australian-born cases, 5.2% had a parent who was born in Asia, compared with 6.6% of Australian-born children in the population ($\chi^2 = 0.96$, $P = 0.3$).

Family history

Concerning family history of IDDM, 6.9% of the cases had one or more affected first-degree relatives (5.6% with one and 1.3% with two affected relatives). One percent had an affected mother, 2.0% had an affected father, and 4.6% had one or more affected siblings. There was no significant difference in the age at onset when comparing cases with and without an affected first-degree relative (median 9.6 vs. 9.4 years, $P = 0.9$).

CONCLUSIONS — By using two independent sources for identifying cases, the ascertainment in our study was close to being 100% complete. We found an age-standardized incidence rate of 14.5/100,000 person-years in New South Wales in the middle of the worldwide range. When CIs are considered, this is similar to rates found previously in Australia (12–14) and in other predominantly Anglo-Saxon populations (15–18). An exception is the significantly lower incidence rate found by a nationwide study in New Zealand, but this study relied on hospital records and gave no estimate of the completeness of case ascertainment (19). Using several sources of ascertainment, a higher rate was found in the Canterbury region of the South Island of New Zealand (15). However, only about 2% of the population of the South Island is Maori, compared with 10% of the more densely populated North Island (19).

As in other studies (16,20–22), we observed a seasonal variation with more cases in the winter months. A seasonal pattern suggests a role for environmental factors, such as viral infection, that may hasten the appearance of clinical diabetes by increasing insulin requirements or by accelerating autoimmune β-cell destruction. The seasonal pattern we found was accounted for by the 10- to 14-year age-group. It was not evident in children presenting at a younger age, in whom the progression to overt diabetes may be more rapid and less affected by exogenous factors.

IDDM has been thought to be very rare among Aboriginal children. A statewide prevalence survey of Western Australian schoolchildren, of whom 4% were Aboriginal, did not find a single Aboriginal case of IDDM (23). In contrast, we

found that IDDM occurs in Aboriginal children with a frequency comparable to that in the rest of the population. Larger numbers will need to be studied before any conclusions can be drawn regarding the incidence among Asian children in Australia. The incidence of childhood diabetes in Asian countries is very low (1,24), and follow-up data from this register will yield important information on incidence rates for Asian populations living in Australia compared with their countries of origin.

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